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ABSTRACT

A study examined parents' attitudes about normalization and their decision about out-of-home placement for their children with mental retardation. The sample consisted of 9 parents who had requested institutional placement, 28 parents who had requested group home placement, and 23 parents who had not requested out-of-home placement. A questionnaire obtained demographic data as well as attitudes about normalization through a 20-item, 5-point Likert scale which measured the degree to which each respondent agreed with principles and practices of normalization in the context of his or her own child. Data did not document a relationship between type of residential placement preferred and attitude about normalization. In general, mothers answered the questionnaires. Parents generally agreed on 11 items which were more philosophical in nature (e.g., mentally retarded children should have opportunities to pursue desires, need warmth and affection as much as anyone else, have the same basic rights and needs as anyone else, and should dress like other nonhandicapped children their age). Parents typically disagreed on 6 items, especially those involving mainstreaming their mentally retarded child in the public school. Nine questionnaire items elicited relatively neutral responses. In general, results indicated that parents agreed with the conceptual/philosophical aspects of normalization but not with the means by which this principle is implemented. It is concluded that if professionals expect parents to engage their mentally retarded children in normalization activities, they need to support parents in carrying out this responsibility by involving them in the planning and programming of services. References and the study instrument are appended. (CB)

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UNDERSTANDING PARENTS' ATTITUDE ABOUT NORMALIZATION

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INTRODUCTION

Underlying the current policy of deinstitutionalization is the principle of normalization which assumes that the least restrictive and most normal environment best facilitates the growth and development of individuals with mental retardation. Consistent with this perspective, parents are expected to cooperate with normalization activities. Parental cooperation, particularly in relation to residential care may be evidenced by: parental approval for transfer of their son or daughter from an institution to a community-based residential facility; on-going parental care-giving within the family home (not requesting out-of-home placement); and when no longer able to provide caregiving, parental request for community-based residential placement.

Yet, practice experience yields the observation that some parents do not cooperate with normalization and in fact, may even create barriers to the provision of services considered to be in keeping with the normalization principle. Such a situation leads to discrepancies between the social worker and the family over the identification of needs and services for the individual with mental retardation. Often, the social worker, acting in accordance with the service delivery system that identifies the individual with mental retardation as the "client", the policy of deinstitutionalization, and the principle of normalization, will take on the role of advocate for the individual with mental retardation. As the advocate, the social worker might very well be pitted against the parents in attempting to facilitate service delivery. Although the explicit issue (for social work practice) is compliance with the policy of deinstitutionalization and the principle of normalization, the implicit issue is the good/rights of the individual with mental retardation versus the good/rights of the family. The question emerges then as to how we might

understand this issue or these descrepancies in order to facilitate service delivery. It is suggested that we need to redefine our "client" so that the "client" becomes the parents and the individual with mental retardation. In order then to better understand our "client" we need to understand parents' attitude about normalization.

BACKGROUND

Theoretically, attitude can be defined as behavioral intent. Therefore, if we know a person's attitude about normalization, we theoretically should be able to predict how that person will act in situations related to normalization activities. Although normalization focuses on the individual with mental retardation, it impacts on parents by identifying them as the primary caregiver and therefore responsible for assuring that their son or daughter receives care consistent with the normalization principle. Since parents are a major resource in the care and habilitation of their children with mental retardation, their attitude about normalization should be an indicator of the extent to which they will engage their children in normalization activities.

Despite the volume of literature related to attitudes about deinstitutionalization, there is a lack of literature on attitude about normalization (Gottlieb and Corman, 1975; Gottlieb and Siperstein, 1976; Meyer, 1980). Although deinstitutionalization and normalization are often discussed together, they are not the same concept. Whereas deinstitutionalization refers to promoting a less restrictive and more "normal" residential alternative, normalization relates to integration of the individual with mental retardation into the mainstream of society. Only one study (Ferrara, 1979) was located which specifically addressed parental

attitude toward normalization activities. Ferrara found a discrepancy in what parents think and in what professionals think parents think. She also found that the concept of normalization was supported in theory but not in application (Meyer, 1980). Given these findings there is need for professionals to re-examine their assumptions about parental support of the principle of normalization and for professionals to acquire additional empirical data about parents' attitude about normalization. Thus, the inherent threat to normalization, that of lack of parent support, can be addressed and resolved before major overt conflicts about residential placement occur between parent's decisions/wishes and their children rights.

THE STUDY

A study was conducted part of which attempted to document the relationship between parents' attitude about normalization and their decision about out-of-home placement for their children with mental retardation. A three group, correlational design was used. The sample consisted of those parents who had requested insititutional placement (Group 1, N=9), parents who had requested group home placement (Group 2, N=28), and those parents who had not requested out-of-home placement (Group 3, N=23). The population pool included parents awaiting institutional placement at Great Oaks Center, Silver Spring, Maryland and parents who were members of the Baltimore Association for Retarded Citizens, Baltimore, Maryland.

A mailed questionnaire which contained a demographic instrument as well as the attitude toward normalization scale, was the method used to collect data. An overall response rate of 35% was obtained and was obtained and this involved a total N of 65 responses. Data was analyzed by means of the Statistical Package for the Social Sciences (SPSS) which included both descriptive and inferential statistics.

FREQUENCY DISTRIBUTION OF RESPONDENT CHARACTERISTICS ACCORDING TO DECISION ABOUT RESIDENTIAL PLACEMENT

	NO PLACEMENT	GROUP HOME	INSTITUTION
	N = 23	N = 28	N = 9
Respondent	69% mother	71% mother	55% mother
Average Age	62	55	54
Marital Status	56% married	60% married	77% married
Income	73% < $20,001	73% < $20,001	28% < $20,001
Occupation	69% retired/hm	44% retired/hm	44% retired/hm
Education	11 grades	12 grades	12 grades
Religion	95.6 affiliated	100% affiliated	87.5% affiliated
Race	52% Caucasian	75% Caucasian	66% Caucasian
Health	65% good/excellent	64% good/excellent	66% good/excellent
Families with siblings at nome	11 (47%)	12 (42%)	4 (44%)
Age range Siblings	1-36	3-31	1-23

Overall sample includes parents who are older than parents surveyed previously (63% ≥ 55 years of age), with mostly intact marriages (60%) and incomes of less than $20,001 per year (66%). The majority of the respondents were caucasian (65%), had at least a high school education (69%), were affiliated with some religious denomination, and reported good or excellent health (65%). Most respondents just had their child who is mentally retarded living at home (> 50%).

FREQUENCY DISTRIBUTION OF
CHARACTERISTICS OF THE INDIVIDUALS WITH
MENTAL RETARDATION ACCORDING TO PLACEMENT DECISION

	NO PLACEMENT N = 23	GROUP HOME N = 28	INSTITUTION N = 9
Age	33.6	27.4	20.4
Gender	60% male	53% male	77% male
Degree-MR	82% moderate	60% moderate	55% moderate
Functional Skills	15.0	15.1	13.5
Self-care Skills	17.0	16.5	11.4
Community Living Skills	7.1	8.5	4.4
Behavior	9.4	9.4	8.1
Overall Level of Functioning	48.2	49.8	40.3

Overall, most of the individuals with mental retardation were over-age for special education services and were described as moderately mentally retarded. Also, most of these individuals were described as having adequate functional skills and being fairly independent in self-care skills, but dependent in community living skills. Social behavior for this sample was fairly non-problematic.

FINDINGS

Table 1 provides the distribution of demographic characteristics of respondents or parents, according to their request for residential placement. A summary of the sample as a whole is also contained on that table. As evidenced by those results, the groups can be considered comparable.

Table 2 depicts the characteristics of the individuals with mental retardation according to the type of residential placement that had been requested for them. This table also contains a summary of these individuals as an entire group.

It should be noted that the data did not document a relationship between decision about residential placement and attitude about normalization. Because this finding seemed conceptually/theoretically inconsistent, the attitude about Normalization Scale was reexamined.

ATTITUDE ABOUT NORMALIZATION SCALE

The parents' attitude about normalization scale is a twenty (20) item, five point Likert Scale (ranging from 1 strong disagree to 5 strongly agree). This scale was developed in 1983 from the previous work of Ferrara (1979), Gottlieb and Corman (1975) and Gottlieb and Siperstein (1976). Essentially the scale attempts to measure the degree to which the respondent agrees with principles and practices consistent with the principle of normalization in the context of his/her own child with mental retardation. The reliability of this scale, based on 49 complete cases, is .76 (Cronbach's Alpha) which is an indicator of internal or inter-item consistency and is at an acceptable level. (See attitude about normalization scale in Appendix A)

DISTRIBUTION OF RESPONSES

ON

PARENTS' ATTITUDE ABOUT NORMALIZATION SCALE

ITEM	AGREE/STRONGLY AGREE	DISAGREE/STRONGLY DISAGREE	NEUTRAL
1	46	3	13
2	55	3	3
3	58	4	0
4	12	36	10
5	31	22	8
6	45	11	5
7	38	11	14
8	32	15	14
9	32	17	11
10	13	36	12
11	49	10	3
12	58	2	1
13	31	22	8
14	59	1	2
15	18	25	18
16	41	6	11
17	60	2	0
18	20	29	13
19	51	5	3
20	59	2	1

Range in total score possible - 20 to 100
actual range - 58 to 97
average score - 75.6

The possible range of scores for this scale is 20 to 100 whereas the actual range for this sample was 58 to 97. The average score for the total sample was 75.6 and the average scores for each of the groups were: Group 1 = 70.4; Group 2 = 77.5; and Group 3 = 75.4. As noted previously, because these scores were not significantly different, (a theoretical inconsistency),the attitude about normalization scale was re-examined.

Table 3 shows the distribution of responses for the entire sample. The five categories have been collapsed to three (agree/strongly agree; disagree/strongly disagree; neutral) in order to better illustrate the trends in the agreement and disagreement of particular items.

In Table 4, one can see the items (N=11) for which a good proportion of the sample agreed. These items generally address the philosophical or conceptual aspects of normalization.

Table 5 reflects the items (N=6) for which a good proportion of the sample did not agree. These items generally relate to the manner in which the normalization principle is operationalized, and specifically focus on integration of the individual with mental retardation into the mainstream.

Finally, Table 6 shows those items (N=9) for which a fairly large number of neutral responses were noted. These items include those that address the integration of the individual with mental retardation into the mainstream as well as those that address the value or benefit of habilitation programs.

Of these three "created" subscales, only the one reflecting items relating to the manner in which normalization is implemented has an acceptable reliability (.76 Cronbach's Alpha) and therefore could be used for further statistical analyses of the data. Although there are some limitations to the research itself and the attitude about normalization scale, the findings are quite helpful in our understanding of

AGREE ITEMS

ITEM	CONTENT
1	Other parents to let "normals" play with MR
2	Right to public education
3	My child should dress like non-MR's his/her age
6	Should expect to participate in community activities
11	Should not be placed in an institution
12	Has same basic needs as anyone else
14	Has same basic rights as anyone else
16	Value of habilitation programs
17	Needs warmth and affection as anyone else
19	Habilitation programs should be available
20	Have opportunity to pursue desires

Items are scored such that the response reflects the degree of agreement with the principle of normalization. Thus, these items consistently received scores of 4 and 5 for the majority of this sample.

This subscale was identified as philosophy and has a reliability coefficient of .60 (Cronbach's Alpha).

DISAGREE ITEMS

ITEM	CONTENT
4	Integration in public school
5	No separation in the kinds of community services
10	Integration in public school
13	Integration in the community
15	Integration in "play" situations
18	No separation of community services

Items are scored such that the response reflects the degree of agreement with the principle of normalization. Thus, these items consistently received scores of 1 and 2 for the majority of this sample.

This subscale was identified as segregation and has a reliability coefficient of .76 (Cronbach's Alpha).

NEUTRAL ITEMS

ITEM	CONTENT
1	Other parents to let "normals" play with MR
4	Integration in public schools
7	After 21, chance to live away from home
8	Should be cared for at home
9	Programs not too expensive for actual gains
10	Integration in public schools
15	Integration in play situations
16	Value of habilitation programs
18	No separation of community services

parents' approach to the policy of deinstitutionalization and the principle of normalization.

DISCUSSION AND RECOMMENDATIONS

The results of the re-examination of the parents' attitude about normalization scale support earlier research (Ferrara, 1979) which documented that parents agree with the conceptual aspects of normalization but not with the means by which this principle is implemented. Because only two (2) studies to date report such findings there is need for more widespread research so as to document the extent of such attitudes. However, preliminary to further research, additional work must be completed on the attitude scale so as to improve its reliability and validity. Especially important is the clarification of items whose wording is somewhat ambiguous and the elimination of the neutral category so as to obtain a better indication of potential actions by parents. Also, items relative to an adult population of individuals with mental retardation need to be included since this population more so than other age groups may in fact be more isolated from the mainstream.

The professional sector may be in a fine position to utilize their new knowledge of parents' attitude about normalization to influence social policy. There is something about the current normalization activities that parents do not like. Do they seek more protection (as evidenced by their disagreement with items on integration in the school and community) or more pragmatism (as evidenced by disagreement and neutral responses to items dealing with the value of habilitation programs) in the service delivery system? Does the reality of risk of exposure of their already vulnerable children outweigh the opportunity for their ongoing growth and development?

Given the expectation of the professional sector for parents to engage the individual with mental retardation in normalization activities, it behooves us to offer services that will support the parents in carrying out this responsibility. Involving the parents in planning and programming services in addition to the traditional services of education and counselling may serve to influence parents' attitude about normalization and consequently their actions/behaviors relating to involving their children in normalization activities.

Finally, professionals need to acknowledge the breakdown in the normalization syllogism ("normalization is best for the growth and development of individuals with mental retardation"; "parents want what best for their children with mental retardation"; therefore parents want normalization") and recognize the parents' perspective. Parents' goals for their children with mental retardation are tempered by numerous factors including their experiences with their child, the service delivery system and with the responses from the "normal" population. Thus, a partnership or redefinition of the client needs to be established. Perhaps by combining the pragmatism of the parents and the idealism of the professionals, effective advocacy can occur which will result in the physical, social and psychological integration of individuals with mental retardation into the mainstream of society.

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INSTRUCTIONS: Below are statements that relate to your feelings about normalization for your child who is mentally retarded. Please rate how much you agree with each statement by using the following rating categories.

1 - strongly disagree
2 - disagree
3 - neutral - neither agree nor disagree
4 - agree
5 - strongly agree

	For Computer Use
1. A parent should allow his "normal" child to play with my child who is mentally retarded. _____	_____ (48)
2. My child who is mentally retarded has a right to public education. _____	_____ (49)
3. My child who is mentally retarded should dress like nonretarded children his/her age. _____	_____ (50)
4. I want my child who is mentally retarded to attend a public school that has classes for nonretarded children. _____	_____ (51)
5. No separation should be made between the kinds of community services available for my child who is mentally retarded and the kinds of services available for nonretarded children. _____	_____ (52)
6. My child who is mentally retarded should not expect to participate in activities available in the community. _____	_____ (53)
7. After he/she is 21, my child who is mentally retarded should be given a chance to live outside the family home. _____	_____ (54)
8. My child who is mentally retarded should be cared for at home. _____	_____ (55)
9. Programs for mentally retarded children are too expensive for what my child who is mentally retarded gains from them. _____	_____ (56)
10. My child who is mentally retarded should not attend public schools with "normal" children but should go to a special school where "normal" children do not attend. _____	_____ (57)
11. My child who is mentally retarded should be placed in an institution. _____	_____ (58)
12. My child who is mentally retarded has the same basic needs as any other individual. _____	_____ (59)

13. There is no place in the community for my child who is mentally retarded. _____ (60)

14. My child who is mentally retarded has the same basic rights as any other citizen. _____ (61)

15. My child who is mentally retarded would be happiest playing with others who are also mentally retarded. _____ (62)

16. Because of the limited ability of my child who is mentally retarded, habilitation programs are not worthwhile. _____ (63)

17. My child who is mentally retarded needs warmth and affection just as any nonretarded person his/her age. _____ (64)

18. Community services for my child who is mentally retarded should be located apart from services for nonretarded persons of the same age. _____ (65)

19. Despite their cost, habilitation programs appropriate for my child who is mentally retarded should be available. _____ (56)

20. My child who is mentally retarded should have the opportunity to pursue some of his/her desires. _____ (67)

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